



**ANNUAL
REPORT**

LEADERSHIP 2010



Board of Directors

John Mayer, Julia Hetherington, Randy Beall, Maggie Miller, Percy Huston, Tina McGrevy, Phil Reudi, Mary Kate McCauley
Not pictured here but pictured below is board member Ann C.M. Smith, M.A., D.Sc.(hon).

MISSION STATEMENT:

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMS.

From the beginning PRISMS has been a partnership between the families affected by SMS, and the researchers who study it. PRISMS (an acronym for Parents and Researchers Interested in Smith-Magenis Syndrome) was formed around a kitchen table by Maggie and Scott Miller (parents of Deirdre) and Ann C.M. Smith, M.A., D.Sc. (hon) in 1993. They knew two things: much more research was needed into this rare syndrome, and the families who deal with SMS needed information and support.

In the ensuing 17 years, there have been many accomplishments by researchers including delineation of

characteristics, medical management guidelines, better understanding of SMS at the molecular level, and discovery of a critical gene that allows for more accurate diagnosis. Many of these professionals also contribute significantly to PRISMS by serving on our Professional Advisory Board.

PRISMS now provides ...

- Conferences that combine research information with support from the other parents
- A website that provides instant access to in-depth information about SMS



- A quarterly newsletter with heart-warming stories, as well as the latest research info.
- Facebook, Twitter and E-Blasts
- And sometimes, most importantly a personal phone call, an email, a shoulder to cry on, an answer from experienced parents who truly understand.

The year 2010 was another very busy one for PRISMS. We continued the planning process for our 7th International Conference to be held in Denver in 2012. We worked to identify co-committee chairs (Nina Kelly and Shannon Jantzi), and now have a program committee that is already hard at work. Building on the success of our past conferences, we produced a detailed conference-planning manual to help guide this new committee. The PRISMS Board of Directors met in October at the future site of the 2012 conference.

With the help of Scott Miller, we began a major redesign of our website. Our current site will be retired, and the new site will be launched in the near future. Our hope is that this new site will help improve the information we deliver to our families, and allow us to connect our families in new ways.

We saw great support from our members, with many of them hosting fundraising activities. These events continue to generate tremendous awareness in addition to the much-needed funds that were raised.

In 2010, we continued our partnership with the Camp Breakaway organization to develop a U.S. camp for SMS individuals and their families. Our first pilot camp will be held in September 2011 at Covenant Harbor in Lake Geneva, WI. Gail Kopp is leading our fundraising effort to support this camp. Camp Breakaway has successfully served many Australian SMS families for several years. It is our hope that this will help us foster family education, respite, and research activities.

We continued to improve our newsletters and other forms of communications in 2010. Julia Hetherington, our editor, and her committee have continued to make significant improvements in our quarterly newsletter, Spectrum. An awareness poster was created and distributed to therapy clinics. We now have a Facebook page (thanks to Denise and David Smith), and have continued to use email to communicate information to our members.

After many hours of planning, the first PRISMS Research Alliance Meeting was held in May 2010 at Elwyn outside of Philadelphia, PA. The PRISMS Professional Advisory Board, select PRISMS board members, and parents met with prominent researchers to gather information and prioritize future PRISMS research projects. The first project to come from this meeting was a scientifically designed questionnaire that many of you were asked to complete. We hope to obtain significant research data, including the similarities between Autism and SMS, and the medications, complementary alternative methods, and therapies that are working for families.

Of course, none of this work could be accomplished without our great group of volunteers. PRISMS is run solely by volunteers; most are parents of children with SMS, and all lead very busy lives. Our board members and other volunteers donate their time free of charge in order to make our programs successful. Board member, John Mayer, has added "Membership Committee Chair" to his many contributions to PRISMS.

In 2010, after helping us complete our successful 2009 audit, Jeri Gawlowski resigned from the board. We appreciate her many years of dedicated service and numerous contributions. Phil Ruedi joined the board as Treasurer in April 2010. Phil has already shown us what a valuable asset he is by strengthening

some of our processes and procedures. His expertise will be invaluable as we get closer to our next conference. Mary Kate McCauley joined the board in February 2010. Mary Kate has a wealth of experience and shares our vision, mission, and passion. We are excited to have her serve. Tina McGrevy joined the board in July 2010. Tina has conducted several successful fundraisers for PRISMS, and now leads our efforts in that area. Our hope is that her enthusiasm will spread. We are very excited to have her. Finally, Percy Huston and I renewed our board terms for another 3 years.

Since 1993, PRISMS has served as the primary source of information and support helping affected families. Today, we serve not only those in the US, but families throughout the world. Together we are making a difference in the lives of so many!! Again, thank you for your continued support. I look forward to a great 2011.

Sincerely,
Randy
Randy Beall
PRISMS, President



FINANCE 2010

PRISMS financial goals include funding its continuing program services, supporting research opportunities, and preparing for the 2012 conference. Membership contributions, product sales, and fundraisers are all important components of our strategy to fulfill these goals. After funding the 2009 conference, there was an almost \$30,000 decline in assets. In 2010, PRISMS received significant support from its members through individual donations, and also through several fundraisers, increasing assets by \$37,000. This puts PRISMS in a strong financial position as the significant costs of operating the 2012 conference come closer.

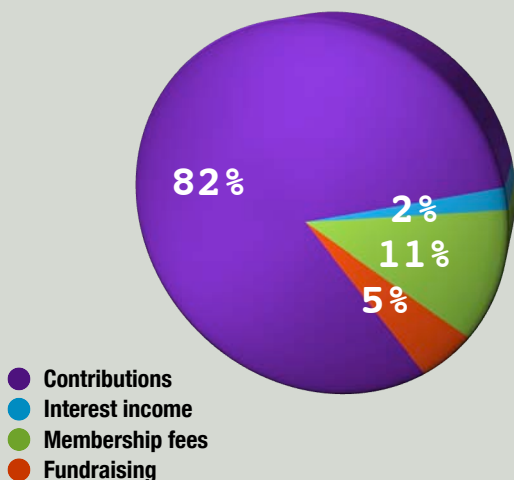
In 2010, over \$10,000 in donations and funds raised were used directly to fund general research as well as specific research studies, such as Dr. Elsea's Well Sibling study. When including the costs of PRISMS'

sponsorship or the SMS Research Alliance in May 2010, over 34% of 2010's expenditures were research related. Comparing 2010 to the last non-conference year (2008), total support and revenue increased by 21%. Membership fees increased 32%, and donations and fundraising increased by 25%. Interest income declined 71% due to lower interest rates. Total expenditures decreased 18% in 2010 compared to the last non-conference year of 2008.

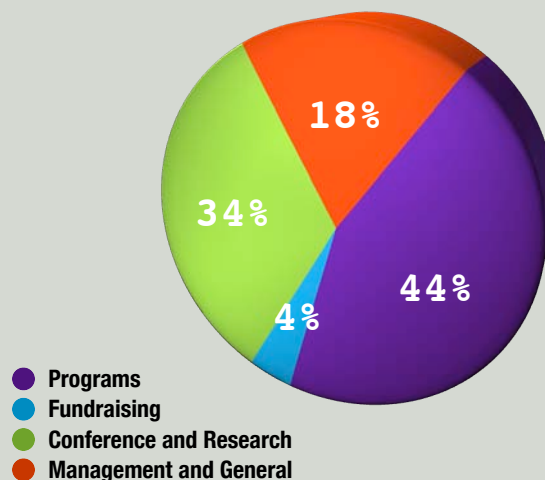
PRISMS is committed to supporting its membership through its programs and research. It is through the hard work of our dedicated membership that these goals are realized.

A copy of the 2010 audited financial report is available upon request.

REVENUE



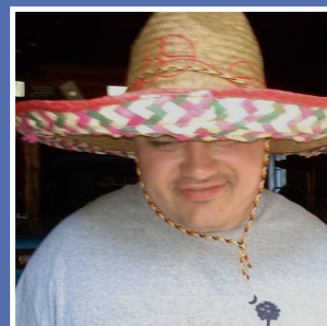
EXPENSES



SUPPORT AND REVENUE	2009	2010
Conference	44,335	----
Grants	21,700	----
Contributions	52,167	66,509
Membership fees	9,918	9,244
Interest income	2,384	1,407
Fundraising	20,764	4,207
Total	151,268	81,367

EXPENSES	2009	2010
Conference & Research	156,004	14,813
Programs	12,251	19,557
Management & General	8,435	8,048
Fundraising	4,443	1,770
Total	181,133	44,188

TOTALS	2009	2010
Increase/decrease in total assets	-29,865	37,179
Total assets, beginning of period	204,349	174,484
Total assets, end of period	174,484	211,663
Total assets consist of:		
Cash	173,634	209,465
Prepaid insurance	850	2,198



"Our children are consistently inconsistent; always challenging us to enter their dance and teaching us the steps we need to change a jitterbug into a waltz."



DONORS

2010



Our Donors Are Our Heros!

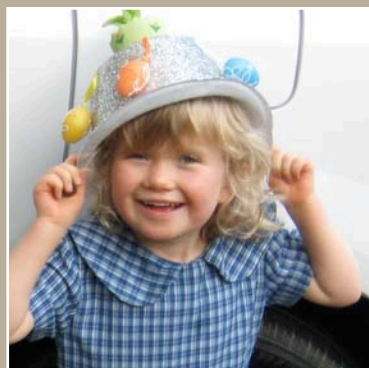
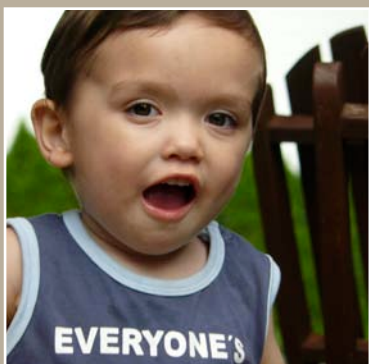
Donors from Jan 1 - Dec 31, 2010

\$1-\$500

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\$1,000 and over

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 Do Fun Stuff (Ryan Marshall)
 Fairfield POA (Pereira family)
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 Jessica & Mark Kirklin
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 Dave Rinebolt
 Robert Schannep
 Laura Staich & Philip Ruedi
 Sienna Steps 5K (Longman family)
 Kevin Traynor, Sr.
 Dayton High School 5K (Weil family)
 Lodis Group

In Kind Donations:

Rio Friday
 Carey McKinney
 Scott Miller
 Ann Smith
 Paul Wang

**Thank you
 to each of our
 donors!!**

MEMBERSHIP

2010



At the end of 2010, there were 261 individuals or families who were members of PRISMS. Our membership came from 44 states and the District of Columbia, and from nine countries around the world. (States currently without members are Hawaii, Indiana, Mississippi, Nevada, South Dakota, and West Virginia – who do you know in those states who might benefit from a membership with PRISMS? Please help us reach out to those families, and invite them to join us!)

During the year, PRISMS formed a Membership Committee with a goal to improve communication with and service to members. Among our efforts has been creating a Facebook page and discussion group, and sending personal notes as well as New Parent Packets to new members. In 2011 we will work to increase the number of members, capture the interest of those who have let their membership lapse, and conduct a survey to better learn how the organization can help and support families and SMS individuals.

Thanks to all of you who are part of PRISMS – and to the Membership Committee for their efforts: John Mayer, David and Denise Smith, Tara Carlton, and Mary Kate McCauley.

2010 PRISMS MEMBERS

Alabama

Laura & Matt Markus

Alaska

Barbara McClenahan

Arizona

Patty & Steve Loyer
Ines Oppenheim

Arkansas

Rosanne Hindsley

California

Mark Brown
Austin & Judy Carney
Peter Cooper-Ellis & Sarah Weck
David Crummey
John & Priscilla Diamond
Paul & Susan Diamond
Diane & Joseph Erth
Tony Fahl
Howard Gitlin & Charles Smith
Mary Ellen Hesse
Jeanine & T.D. Hetherington
Mary Hetherington
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Krista & David Karr
Charlene Liao & Liqun Luo

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Gail & Bruce Napell
Frank & Adela Nevarez
Achille & Joan Paladini
Laura Paladini
Kim & Tom Pastore
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Lexa & Kurt Schoppe
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Tom & Lee Varallo
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Louise Tortora
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Linda Johnson

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Kathy Hofmann
Irene Karpowicz
Melissa & Dan Longman
Carol & Stan Triantafellu
Christopher J. & Laura P. Wells

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Lesslie Carnahan
Amanda & Charlie Graham
Lowry Reid
Anne Ryder
Rochelle & Paul Wright

Idaho

Monica & Mark Peterson

Illinois

Marsha & Gary Bach
Joan & Michael Campione
Kevin O'Connor & Dana Deane
Christine & Joey Grzybowski
Oliver Howell
Kenneth & Mary Koppers
Julianna & Jeremy LaPlant

Bill & Janet Manning

Nadia & Dan Marler
Robyn & Steve Mogul
Linda & Dan Tortorelli
Margaret & Robert Tortorelli
Carol & Glenn Wollschlager
Deann & Jeff Yerik

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Karen & Chuck Friedman
Todd & Jennifer McQuown
Jan & Keith Rolston

Kansas

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Ryan Peters
Van & Linda Peters
Katy & Frank Tra
Todd & Shiloh Frese Walter

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Jean Weil

Louisiana

Ashton & Lynn Cher

Maine

Susan & Daniel Longfellow
Jon R. Wiley

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Kerry Hill
Jim & Jamie Humphreys II
Yukiko & Tetsuya Ichino
Mary & Paul Miller
Joanne Sowards
Mary Unglesbee
Ruth & Dennis Unglesbee
Ronnie & Janet Wagoner

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Maryann & Paul Duzan
Rich & Julie Giurleo
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George Kohout & Debra Orgera
Diane & Michael Petrucci
Joan & Peter Sherman
Philip Ruedi & Laura Staich

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Nicole & Jeff Hill
Jim & Irene McCool
Rajeon Potter
Jane Vit
Eva & Greg Wludyka

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Janet Jacobs
Cindy & Jeffrey Linert
Beverly & Marvin Melanson
Mary Kay & Dennis Vierling

Missouri

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Dennis & Tracey Dillon
Wei Zheng & Jian Ping Huang
Jim & Emily Humphreys
Sabrina & Bill Hurtgen
Percy Huston

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Maureen Kelly

Barbara Lovrinic
Caroline Pope

New Mexico

William & Laurel Sellyey

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Marcy Bulger
Dr. Lynn Diamond
Lisa Hutchinson
June & Todd Jacobson
Josephine Lawlor
G. Patrick Lester
Barbara Melamed
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Evelyn Popper
Liz & Bob Pucci
Shonnie Rodriguez
Ida & Richard Ruess
MaryAnn & Ron Zimmer

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Mary McArdle & Anne Green
Monica Moreira
Paul & Benita Soper

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Shannon & Darin Jantzi

Ohio

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Kellie & John Cooney
Joan Currey
Patricia & Steven Engelman
Kristen & Michael Hamilton
Janet & Dennis Hartmann
Kathy Krisko
Kim Manix
Sue McFee
Tina & Charlie McGrevy
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Faith & John Stepic
Cheryl Stevens
James Warman
Cathy Witt

Oklahoma

Tara Carleton

Oregon

Shirley & Donald Dechaine
R. Ellen Magenis, M.D.

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Kristin & Carl Brown
Leslie & Christopher Calzaretta
Nancy & David Cordrey
Milissa Ferry-Pelonero
Brenda Finucane, M.S.
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Mary Kate & Joe McCauley
William & Patricia McDonough
Matthew Oralek
Celeste & Kemal Pegram
Mark & Carol Bivens Roth
Sandy & John Tome
Carol & Gary Zaiser

Rhode Island

Maria Mosher

South Carolina

Debra Frasier
Sharon & Daryl French
Julia & Tom Hetherington
Coye Riley

Tennessee

Olivia McGehee & Jim Scheicher
Christina Tabat

Texas

Carolyn Beall
Mary & Randy Beall
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Margene & Jonathan Morris
Heather & Daniel Wilde

Vermont

Patty & Dan Saunders

Virginia

Gina & Steve Belden
Margaret & Scott Miller
Diane Powers
Shannon Richard
Kristine & Michael Sanford
Ann & Ron Smith
Venessa Stevens

Washington

Estaban & Jennifer Delgadillo

Wisconsin

Mary & Tim Kamp
Alan & Gail Kopp
Linda & David Mills
David & Lynn Moertl
Patti & Terry Schiller

Wyoming

Irene & Dan Knoepfle
Tiffany Helling

Foreign Countries**Australia**

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A. & P. Bonato
Denise Caddy
June Dixon
Stephanie & Nicholas Hanson
Susan & Bryce Hoad
Mary Storch

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Dr. Kerry Boyd
Emely & John Coultis
Eric & Lorna Harris

Denmark

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Israel

Hagai Cohen

Japan

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Mexico

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Netherlands

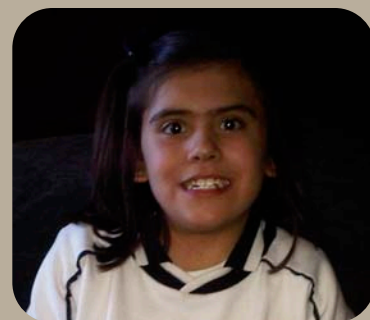
Paul de Jong
Ronald & Carolina deKimpe

Philippines

Kristine & Glen Braden

United Kingdom

Carol Funnell
Sonya Lowe
Patricia van Nederveen



RESEARCH UPDATE

2010

This year PRISMS was able to participate and fund various research projects involving a full spectrum of research areas. We look forward to funding more research projects in the coming year and hope to welcome new researchers to the study of SMS.

Complimentary and Alternative Therapies, (CAM Study): The use of complementary and alternative medicine in patients with Smith-Magenis syndrome. This study will help to provide data to the SMS community on what kinds of complementary and alternative therapies may be helpful in raising children with SMS. Principal Investigator: Rio Friday.

Phase 1 Treatment Trial of Circadian Sleep Disturbance in Smith-Magenis Syndrome (SMS) at NIH: In 2008, researchers at the National Institutes of Health (NIH) began active enrollment for the first controlled treatment trial to determine if bright light alone, or in combination with a melatonin tablet preparation, is effective in treating the sleep disturbance in children with Smith-Magenis syndrome SMS. Principal Investigator: Ann C. M. Smith, MA, D.Sc. (Hon), NHGRI.

***Siblings of Children with Neurodevelopmental Disabilities: An investigation of well-sibling intra-familial relationships:**

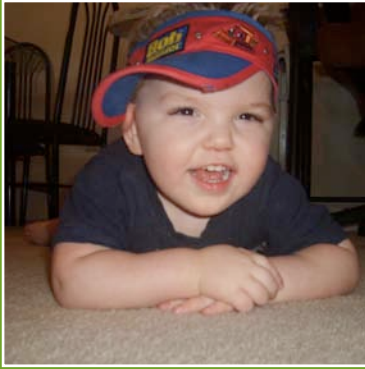
Goals: To examine well-sibling and parental perceptions of sibling relationships in families with at least one well-child and a child with SMS, Down, or Williams syndrome. This study involves the evaluation of social and psychological impacts of well-siblings of individuals with neurodevelopmental disabilities, including Smith-Magenis syndrome, Williams syndrome, or Down syndrome. Principal Investigators: Melanie S. Moshier, Timothy P. York, and Sarah H. Elsea, PhD, Department of Human and Molecular Genetics and Department of Pediatrics Virginia Commonwealth University, Richmond, VA.

***Sleep Analysis in RAI1 Disorders:** Sarah Elsea, PhD, at Virginia Commonwealth University is investigating sleep habits in children with *RAI1* disorders and their parents. These disorders include Smith-Magenis syndrome and Potocki-Lupski syndrome. The purpose of the study is to collect information about how *RAI1* disorders affect sleep habits and behaviors of children with these disorders and their parents, with the goal of finding interventions or tools to improve sleep and behavior for the family. Principal Investigator: Sarah Elsea, PhD.

*Funded by PRISMS

"One of PRISMS' goals is to support and promote research into the causes, management, and treatment of Smith-Magenis Syndrome."





"Our children challenge us to become parents that we never imagined we would need to be. They bring us to places that require unending wisdom, courage, patience, and the ability to love all that they are. They have moved us to become fearless advocates and experts in perseverance and grit. How wonderful that they have molded us to be so much better. Thank you dear children for helping your parents to be marvelous and blessed."

PROFESSIONAL ADVISORY BOARD

PRISMS nine-member Professional Advisory Board (PAB) serves to advise the Board of Directors on medical and scientific matters, and assist in the educational and research activities of the organization. An internationally recognized group of basic scientists and clinicians with expertise in SMS, including the syndrome's co-discoverers (Smith and Magenis), the PAB assists in the development of accurate and effective informational and promotional materials. The board writes and edits articles for Spectrum newsletter, PRISMS website and other publications. They disseminate accurate medical information about diagnosis, management, and genetic

counseling via the regular update of SMS listing published in GeneReviews, the online expert-authored, peer-reviewed disease descriptions. (Note the most recent update in January, 2011). Members of the PAB also respond to ongoing inquiries about clinical, educational, research, and management issues received via info@PRISMS.org from families of persons with SMS, as well as lay, educational, and professional service providers. A major PAB project in 2010 was to work with PRISMS to organize and moderate the 1st SMS Research Alliance.

PRISMS SMS RESEARCH ALLIANCE

The first SMS Research Alliance (RA), convened and sponsored by PRISMS at Elwyn's campus in Media, PA, was held on May 6, 2010. The major goals of SMS Research were to: 1) build collaborative ties among researchers who share interests and expertise in specific priority research areas; and 2) identify specific research priorities on which to focus PRISMS fundraising efforts. The first Research Alliance included PRISMS invited top experts working in the areas of behavior intervention, complementary and alternative medicine, and targeted pharmaceuticals to share their experiences and explore strategies, skills and research ideas that may benefit persons affected by Smith-Magenis Syndrome (SMS). PRISMS

member attendees included a subgroup of Professional Advisory Board (PAB), board members, and several invited parent representatives interested in promoting SMS research. During the one-day meeting, the series of presentations were followed by thought-provoking discussion to identify future promising research areas, potential barriers, and funding requirements, as well as establish key steps necessary to promote and advance collaborative research efforts. The recent SMS study focused on CAM (Complementary and Alternative Medicine), was a direct outgrowth of the first Research Alliance meeting and new collaboration with Dr. Susan Levi's past research in the autism community.

PRISMS - CAMP BREAKAWAY IN THE USA

Camp Breakaway, which is a non-profit group based in Australia, holds respite camps for children and adults with disabilities, and at the same time, provides respite for the families and caregivers. Camp Breakaway offers respite opportunities rarely experienced by any SMS family. The entire family is supported and catered to, all in a safe, nurturing, and therapeutic environment. Siblings can now have that much-needed one-on-one time with their parents. Parents finally get to take a break and rest, relax and rejuvenate, and the children with SMS enjoy a uniquely special time with new SMS friends, while being completely cared for both day and night. The Camp Breakaway respite model has been so successful, that they have now held 4 SMS camps in Australia since 2003. PRISMS is fortunate to have been part of this history, and, we are now going to be able to share in the Camp Breakaway experience by hosting "PRISMS-Camp Breakaway" in the US this coming year!

2003: Camp Breakaway hosted its first SMS camp, inviting 21 families to participate. Ann Smith, (NIH/NHGRI), was invited to attend and present educational sessions in a "casual" atmosphere to the families who attended. Accompanying Ann Smith, (also from the Natural History Study of SMS at NIH) were Wally Duncan, PhD, sleep biologist and Beth Solomon, SLP, speech pathologist.

2006: Camp Breakaway hosted its second camp, where 19 SMS families attended. Ann Smith, Wally Duncan and Beth Solomon also attended the second camp. They presented information to all of the families, including the results of the data from

the first camp, while running another SMS Research Clinic during the camp.

2008: Camp Breakaway hosted its third SMS camp, with 18 families in attendance. This time, Ann Smith was accompanied by Gail Kopp and Mary Beall, both mothers of SMS children in the US, and members of PRISMS. These women were affectionately known as "Team USA." Gail and Mary assisted Ann in the clinic, and also shared information and strategies with the Australian families. More importantly, they saw first-hand how the camp was run, and the tremendous benefits the entire family members received while attending Camp Breakaway. The seed was planted, and Gail and Mary were determined to make this camp a reality in the US.

"Once again, another successful camp. Our children were taken care of 24/7 by such wonderful, giving volunteers, to access Team USA expertise and to spend quality time with parents going through exactly the same situation as we are. Thank you. We are eternally grateful."

~ Jodie and Andrew Pearson

2009: One of the directors of Camp Breakaway and two staff members, (Michelle Price, Jodie Davis, Gae Miller, respectively), were invited to present at the PRISMS 6th International Conference in Reston, VA. They shared the incredibly positive events of the past three Camp Breakaway/SMS Camps, and our



conference attendees enthusiastically received their wish of bringing the Camp Breakaway model to the US. While they were here in the US, they toured three prospective sites suitable to hold a PRISMS-Camp Breakaway camp. Gail Kopp was their travel guide, and soon-elected chair of the PRISMS-Camp Breakaway project!

2010: Camp Breakaway held its fourth SMS camp, which included 14 SMS families from Australia. Ann Smith and Gail Kopp attended the camp again (Team USA), along with one of the directors of Covenant Harbour, a camp in Wisconsin. Besides participating in the usual fun activities of the camp, planning was begun on prospective camp(s) in the USA.

Gail Kopp and her committee of volunteers have begun fundraising efforts to support the PRISMS-Camp Breakaway program. The camp will use the same model as Camp Breakaway in Australia, and will be staffed with trained volunteers from the Australia camps. We look forward to our joined efforts with the team at Camp Breakaway, and the exciting events that will come from this partnership!

SUPERKID

SAMANTHA BROWN

Sami was born February 4, 1993. The same day, same month, and same year that PRISMS was formed. What a coincidence!

Sami has recently celebrated her 18th birthday. She is a real teenager now. She loves to listen to music, and walks around most of the day with earphones blasting the sounds of electric guitars into her eardrums, just like most kids her age do! Laura is constantly saying, "Sami, turn that down." She also loves to sing Karaoke. She was given a Karaoke set last Christmas. Yes, Sami loves it, but the entire household, including the dogs run out of the house like the fire alarm went off whenever she starts singing! Not that she has a bad voice, but she likes to repeat a verse she is fond of over, and over, and over again.

Her favorite performer is Lady Gaga, so for her 18th birthday Laura had a Lady Gaga performing Sami's favorite songs at her party. The Lady Gaga was picked up in a white Limousine and driven to Sami's house to surprise her. Lady Gaga, Sami, and all the guests were driven in the limo to a restaurant for lunch. We were hoping the crowds wouldn't mob the celebrity asking for autographs. After all, this was Sami's personal celeb!

Like all teenage girls, she loves to go to the mall and look around. She just recently got the impulse for "fashion." She received a pair of Ugg boots, and looked at the label and discovered they were made in China, though bought from the website in Australia. So who is smarter, the teenager or the parent? It's amazing just how smart our SMS kids really are. It seems their intelligence and worldliness is locked up in a little box just waiting and wanting to be released. What really goes on in there; if only we knew!

Since her discovery of name brands, she is very fond of her mother's clothes now. Quite often she goes to school in her mother's tops, trousers and jackets, but not the shoes, they are too small; well, except for the Ugg's! However, we have also seen the mother in some of Sami's outfits as well, even if they are a bit big on her!

It's amazing: she is an expert with dogs. She knows every breed there is, and can sniff them out in a heartbeat! The other day there was a Tibetan Terrier, and we mistakenly called it a Tibetan Spaniel, and we were promptly corrected and chastised!



Like everyone, she loves the ice cream shop! Sometimes we find an excuse to take her so we can indulge ourselves as well! It may take up to 15 minutes for her to decide to order the same thing she always does! Her favorite is Cookies and Cream with M&M's sprinkled on top, in a bowl with a cone upside down. It takes a garden hose to wash her down when she's finished!

She is working two hours a week now at a department store close by, and has her own little money to herself.

She picked out and bought earrings for her mother for Christmas, and an airplane calendar for her Papa, because she knew he had taken flying lessons--all by herself and with her own "little money" she earned!

We all love her with our very being, and hope her coming into adulthood will allow her a bit of independence and self-assurance, and most of all, good health. Our family feels so fortunate to have this caring, lovable, sensitive person in our lives.

We all certainly love our SMS kids don't we!

Submitted by Sami's grandfather, "Kiki" Paladini. Sami is the daughter of Laura Paladini, and is also pictured on our cover!

WORKING NOW FOR 2011 AND BEYOND

CONFERENCE 2012 JUNE 28 - JULY 1, 2012

PRISMS will be hosting its Seventh International conference in 2012. The Conference will be held from June 28th – July 1st, 2012 in Denver, CO at the Denver Renaissance Hotel. We are happy to be coming back to Colorado where we held our conference in 2002. With the Rocky Mountains as our backdrop, we hope to create new, shared memories as we come together to celebrate our children, while learning new information about Smith-Magenis Syndrome. We look forward to welcoming back our returning families and professionals, and most eager to welcome our new "first time" attendees. This will be a time for fellowship between families from around the world, and a time for collaboration and discussion between professionals and researchers.

The conference planning committee has already begun planning and is working very hard to make our next conference a success. This is an educational conference, and although childcare is available, it will be limited. We will be sharing a lot of information regarding the conference and all the details, including the hotel, in the many months ahead. Please check the website and Facebook page as well for updates. Be sure to keep your membership to PRISMS active to stay on all our e-blasts, too! In the meantime, we hope you can mark your calendar, pencil those dates in, and plan your time to come to Denver. We hope to see you next year!



LAUNCHING OF NEW WEBSITE!



After a great amount of work in 2010, PRISMS is proud to announce the launch of its new website. The facelift also includes new functionality, the ability to renew or join membership online, Spanish translation of certain content, and new photos and articles from families. The site is easier to maneuver and has a more up-to-date look and up-to-date content. We also have added new links, including our Facebook page, and a link to follow us on Twitter. Please also review our updated "terms of use."

We will continue to update the new website and add new content. It has taken many hands to construct the site, and we thank all of our volunteers for their help. Please go to the site, www.prisms.org, and check out our new look.

THANK YOU!

2010



The year 2010 was another successful year for PRISMS fundraising! SMS families from across the country spearheaded events in their local area to raise money for PRISMS, as well as awareness for Smith-Magenis Syndrome.

Golfers on the west coast joined the Pereira family and the Fairfield Police Officers Association in a golf outing. In the Midwest, the Stepic family held a golf outing, and the McGrevy family hosted their fourth 5K run/walk. Todd McQuown of Iowa generously added to the McGrevy 5K donation box with monies he collected in his hometown. In New York, the non-profit organization, Angela's House along with the Gerberg family, chose PRISMS as one of the benefactors of their fundraising event. Runners in Florida joined the Longman family for their 5K race, and students from Dayton High School in Kentucky held a 5K in support of the Weil family. Julia Hetherington (SC) held her second "Pottery for PRISMS" fundraiser with all proceeds from sales

donated to PRISMS. Macy's shoppers throughout the states donated to PRISMS through the annual "Shop for a Cause" event. iTunes listeners purchased "Do Fun Stuff" (Vol.1), which was produced and performed by Ryan Marshall and his artist friends.

Thanks to these many volunteers, PRISMS is able to continue our mission of supporting families of persons with SMS by "sponsoring research and fostering partnerships with professionals to increase awareness and understanding of SMS." Please contact Tina McGrevy at fundraising@prisms.org if you would like more information on how to host a fundraising event in your area.

In the fall of 2010, the fundraising board duties were passed from Percy Huston to Tina McGrevy. Thank you, Percy, for your dedication during your term as fundraising chairperson, and your help during the transition period.

PRISMS wishes to thank blogger, photographer, and SMS parent, Ryan Marshall, for the many hours he spent developing our first charity album, "Do Fun Stuff" (Vol.1). Available on iTunes, "Do Fun Stuff" (Vol.1), contains family friendly tunes from various artists who generously donated their original songs for our cause. One hundred percent of the proceeds will go to a charity trust for a Research Fellowship to fund a graduate student to study SMS. To find out more about this album and see other projects the talented Ryan Marshall is working on, visit his blog at: www.pacingthepanicroom.com.

*Support
Research
Awareness
Understanding*



2010 Annual Report

PRISMS is dedicated to providing information and support to families of persons with Smith-Magenis Syndrome (SMS), sponsoring research, and fostering partnerships with professionals to increase awareness and understanding of SMS.



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